

# Introduction

As HIV invades the body, it creates rippling and profound biological and social consequences for those persons infected. In addition to attacking the body's immune system and causing a broad spectrum of health complications, HIV may present a host of mental and emotional problems by disrupting the infected person's emotional equilibrium, sense of self, relations with others, and purpose in life. HIV also has socioeconomic consequences that affect one's most basic human needs, such as housing, food, financial security, and employment. Substance abuse confounds these issues, leading to deteriorating physical and mental health, and the poor judgment that may result in risk-taking behaviors of both a sexual and criminal nature. When addictions become severe and refractory, every aspect of life is affected.

The very complexity of these biological, psychological, and social needs springing from HIV infection argues in favor of an integrated and coordinated approach to care. Failure to address the needs in any one sphere can lead to a breakdown in the effectiveness of treatment in the others. As HIV approaches its third decade of existence, the changing demographics of HIV infection reinforces the need for service integration and coordination.

## EPIDEMIOLOGICAL TRENDS

In the early days of the epidemic, HIV primarily affected gay white males from a broad range of socioeconomic strata. Since 1994, when the HIV/AIDS Mental Health Services Demonstration Program was launched, HIV rates have increased rapidly among disenfranchised ethnic minorities and women. Today, those infected are more often from communities of poverty (i.e., intravenous drug users and their partners, persons who are incarcerated, individuals with serious mental illness, people who are homeless, and the foreign-born) and those engaged in the sex trade. According to the Centers for Disease Control and Prevention's data from 25 states with integrated HIV and AIDS reporting systems, 63 percent of young persons between the ages of 13 and 24 diagnosed between January 1994 and June 1997 were African American (CDC Update, April 23, 1998). Recent estimates indicate that 25 percent of those living with HIV in the U.S. were infected through unsafe injection drug use, while 15 percent became infected through unsafe heterosexual sex (CDC, 1997).

New and effective medical treatments for HIV, including protease inhibitors, have had a profound effect on those living with HIV. The hope that HIV, for some, has become a chronic, treatable condition instead of a fatal one brings with it an energizing optimism—and a host of additional psychosocial complications. At the same time, there are widespread treatment implications for the future. While the death rate from HIV-related

## ...a changing epidemic...

complications decreased 47 percent between 1996 and 1999, the rate of HIV infection has remained steady for some populations and is increasing in others. With those who are infected living longer, caseloads will increase, and the demand for services supporting adherence to a complex array of medical treatments will climb.

These epidemiological changes, coupled with the complex biological and social needs of a growing number of people living with or affected by HIV, call for a comprehensive, coordinated, and integrated approach to care—one that recognizes the importance of mental health issues in providing services to people living with HIV. A specialized approach to HIV mental health service delivery car-

ries many advantages for the client. Sharing the struggle with others who are living with HIV can provide a sense of mutual support, alleviate the stigma encountered in society, and promote a sense of safety. Issues of confidentiality, risk reduction, advocacy, and medication adherence may be emphasized and effectively addressed with appropriately trained staff. Efforts to reach this alienated and heavily stigmatized population require specialized and targeted approaches that involve close collaboration among a broad range of disciplines and service providers.

As this manual was being developed, three themes repeatedly emerged that bear special significance for the provision of mental health services to people affected by HIV—stigma, multicultural sensitivity, and a biopsychosocial approach to care. Although these themes are woven throughout the Practical Guide, their critical impact upon service delivery warrants highlighting them in this introduction.

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## STIGMA

Central to an understanding of the person with HIV who seeks mental health services is an understanding of the concept of stigma and its corrosive and debilitating effects. The archaic definition of stigma is “a mark burned into the skin of a criminal or slave (Webster’s New Riverside University Dictionary, 1139).” The HIV-infected client often finds himself/herself stigmatized in many ways—for having a fatal, transmittable disease; for being “crazy;” for being gay; for being sexual; for being a substance user; for being African American; for being poor; for being Hispanic; for being an illegal immigrant; for being unemployed; for being homeless; or for being an ex-offender. HIV-related stigmatization constitutes an epidemic in itself—an epidemic of fear, prejudice, and discrimination.

The fear of being stigmatized keeps many from seeking services. It also can prevent many clients from remaining in treatment or adhering to a treatment regimen. The feelings resulting from stigmatization may include fear, shame, distrust, rejection, exile, guilt, isolation, hopelessness, helplessness, alienation, lack of self-worth, powerlessness, and aloneness. Empathy for those facing the painful reality of this multiple stigmatization is what propels many to work in the HIV field.

## MULTICULTURAL SENSITIVITY

An effective HIV treatment team includes clinical providers who are dedicated to the work and possess a depth of knowledge of HIV, mental health, substance abuse, and community resources. The successful worker possesses a sensitivity to, and understanding of, individual differences, different cultures, and subcultures, as well as a broad understanding of the biopsychosocial effects of HIV infection on the client's everyday life.

The culturally competent provider must be able to interact in a way that demonstrates an openness, understanding, and respect for the experiences, value systems, and beliefs of others. The culturally sensitive provider will convey to the client an appreciation of the varied cultural perceptions of power and control over one's life and an understanding of why and how clients may have learned adaptational skills that seem to promote dependency and social marginalization.

Prejudgments—of how persons should have lived their lives, avoided HIV infection, or adjusted to a majority culture that all too often discriminates, stigmatizes, and oppresses—lead to a breakdown of trust. As a result, the therapeutic alliance that is the bedrock of effective intervention may be severely compromised. HIV infection has different meanings in different cultures, communities, and families. A person's internal perceptions of his/her external life is unique and evolves in large part from the individual's cultural roots. Cultures and subcultures have contrasting interpretations of what constitutes

pathology, and the culturally competent provider must tread carefully in making a diagnosis and prescribing treatment.

Providers should be comfortable with diverse educational levels, sexual orientations, physical and mental disabilities, substance use, class, and other psychosocial variables. Staff competence and sensitivity results from ongoing self-reflection that diminishes judgmental thinking and promotes tolerance and a sensitive curiosity toward care. By accompanying clients to public agencies to access services, providers gain an appreciation of power and control differentials. Developing a sensitivity to certain marginalized subcultures requires a willingness to enter a "virtual reality" that sees events and attitudes from the client's perspective.

## A SPECIALIZED BIOPSYCHOSOCIAL APPROACH TO CARE

In 1990, AIDS was described as a paradigm of an illness requiring a biopsychosocial approach. With the advent of new and effective medications, such a designation is increasingly apt. HIV infection is a medical illness caused by a virus often transmitted through socially stigmatized behaviors—unprotected sex and injection drug use—that biologically affects the brain and the immune system. At the same time, a diagnosis of HIV creates a series of immense psychological burdens that occur within a larger, more complex psychosocial arena. As the importance of adhering to complex antiretroviral medication regimens gains acceptance, the spotlight focuses increasingly on the whole person and his/her capacity for medication adherence.

**To increase the likelihood of treatment adherence and to promote wellness, the provider must address client-specific concerns on many levels:**

- **Social and Environmental Circumstances.** These include poverty, access to care, family relationships, housing, financial needs, food, child care, transportation, and legal status. Such concerns may be further complicated by homelessness, incarceration, and prostitution.
- **Psychological Factors.** These include stress; depression; anxiety; cognitive impairments due to HIV-associated dementia; psychosis; mania; pre-existing serious mental illness, including schizophrenia and bipolar disorder; and poor judgment and impulsivity associated with personality disorders. Defense mechanisms, such as avoidance and denial, also may interfere with seeking and accepting treatment.
- **Biological Aspects.** The health issues associated with HIV include the client's medical condition; health of the immune system; symptoms and common opportunistic infections (e.g., of the brain); medications prescribed both prophylactically and for symptom relief; and co-existing chronic illnesses, such as diabetes, renal and liver disease, and high blood pressure.

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The biopsychosocial framework is a useful guide in assembling a specialized HIV mental health delivery system. The model helps the treatment provider to remain alert to the interactivity of disorders and stressors, to frame a complete diagnostic picture of the client, and to construct an appropriate and comprehensive treatment plan.

To provide examples of how this biopsychosocial approach to service delivery may be implemented throughout different stages in the treatment process, the authors will share the experiences of clients served by the Demonstration Program. (Case material has been disguised to protect client confidentiality.) Their stories, as told throughout this manual, will enable the reader to better understand how the social, psychological, and biological factors described in this introduction interact with one another and define the approach to treatment.